Disability Visibility Podcast

Episode 1: Activism and the Disability Community

Guests: Andrew Pulrang and Gregg Beratan

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://disabilityvisibilityproject.com/podcast/

Introduction

[radio static, flipping stations, landing on voices singing]

LATEEF: This is the Disability Visibility Podcast with your host, Alice Wong.

[hip-hop beat transitions to mellow music]

ALICE: Hey there. Welcome to the very first episode of the Disability Visibility Podcast, conversations on disability politics, culture, and media. My name is Alice Wong, and I am honored to be your host.

With a gazillion podcasts out there, you might wonder why this one? Why now? The short answer is I don't see shows about disability culture and politics by NPR or other major media organizations, and there are not that many around. The revolution is here. One podcast, one transcript, one tweet at a time.

Oh yeah, and I just wanna make it clear that Disability Visibility isn't visibility in a literal sense. It's about creating spaces by us and for us. It's about our identity, pride, and culture. It's about sharing our community's stories and our unapologetic lives with the world.

Today's guests are Andrew Pulrang and Gregg Beratan. The three of us are co-partners in #CriptheVote, an online movement encouraging the political participation of disabled people.

This episode was recorded in July, days after the GOP health care bill died in the Senate. We look back on the attempts to repeal and replace the ACA, what Medicaid means to disabled people, and the activism that took place all year long in opposition of the bill, especially the activism by ADAPT, a national grassroots disability rights group that was instrumental in creating what Representative John Lewis calls "good trouble."

Are you ready? Away we go!

[electronic beeping]

ELECTRONIC VOICE: 5, 4, 3, 2, 1!

ANDREW: Um, OK, well, I'm Andrew Pulrang, and I'm one of the three people involved in doing #CriptheVote. I've been physically disabled all my life. I have arthrogryposis. I worked in Center for Independent Living for about 22 years, and 12 of those was as Executive Director.

GREGG: I'm Gregg Beratan. I'm a disabled activist, scholar. I guess I self-identity as neurodivergent. And work as a policy analyst at the Center for Disability Rights. I'm a member of ADAPT, and more importantly, I am also a cofounder of #CriptheVote, along with the two of you.

ALICE: And we have to add that you are actually kind of the originator. You came up with the idea of doing something online, and you were the one that brought Andrew and me into this. So, in a way, you're like the Godfather.

[jaunty accordion music]

GREGG: [laughing] Oh, no!

ANDREW: [laughs]

ALICE: The Godfather!!!!

ANDREW: That works for me.

GREGG: OK.

Reflecting on disability activism in 2017

ALICE: So, let's talk a little bit about just reflecting on disability activism this year, especially let's talk about the GOP health care bill that was in the house, that's known as the ACA. Then, it became the BCRA, and then it mutated into this ORRA. We are talking today on July 29th, and just two days ago, the bill was killed in the Senate. So, let's talk about, I guess, how we're feeling about just the rollercoaster ride and just what you observed and what you experienced.

GREGG: Can we just start by saying let's hope it sticks this time?

ALICE: Yeah!

GREGG: [laughs]

ANDREW: I agree. I was gonna say that's one of my reflections, is that I think that this is probably gonna be something we're gonna have to deal with in some way for at least another couple years, probably, off and on. It feels like we've reached a threshold or a certain turning point, but that doesn't mean it won't come up again.

GREGG: I think the danger will at least last until people start running for mid-terms.

ALICE: Mmhmm.

GREGG: I can't see them trying to pull this during an election unless it's somehow a stunt to play off the Democrats. But I don't know.

ALICE: And also, we have to keep in mind that legislation isn't the only way to dismantle Medicaid or other safety net programs. There's a lot of decisions that can happen from CMS and other departments. So, we all gotta be vigilant on that. I definitely think that what we've seen in terms of people sharing their Medicaid stories, that it'll still really be needed throughout the entire four years of, hopefully just four years. But yeah, I think that it's been really a great awakening in the sense that where finally, non-disabled people have a little sense of what Medicaid is, what it does, and just how many people it reaches.

ANDREW: Yeah, no, I agree. And one of the good things is--and it's just my instinct on it is--six months ago, I would not have said that there would be as much support for Medicaid as there is right now. And not just with the disability community, but overall. I think what you just said is correct that people have woken up to realize that Medicaid is a thing, and that it's a thing that people actually like and appreciate. It's not some sort of crappy, expensive entitlement that nobody really likes. People actually appreciate it. And of course, we have things that we wanna change about it, but as far as-- You know, there was sort of an image before. I think that it was people vaguely thought that even the people that were on it sort of despised Medicaid and wanted to get off it as soon as they could kind of thing. That's just not really the case. You know, surveys show that people who are on Medicaid are overwhelmingly happy with it. And that half the reason that people don't like the marketplace exchanges is because they'd rather be on Medicaid, you know, than pay through the nose for a sort of half-hearted private plan.

ALICE: Mmhmm. And I think it also speaks to one of the reasons why people are satisfied or happy for Medicaid is because they know so many people that aren't insured or discriminated against because of their pre-existing condition. And that we still live in a country where health care is not guaranteed for every single person. So, of course we're gonna be very thankful and reliant on Medicaid, because we're still not at that point where everybody's covered. But I also think that what I really appreciated were these stories about how Medicaid really supported people in education, in public schools. People did not realize the reach of Medicaid beyond poor and disabled people.

ANDREW: Right.

ALICE: And so, I think that's another thing that, "Oh, my parent might be in a nursing home!" Like that might be a risk. Or these kids who need services at school. It's like, oh! Kind of broadening the base of the reality of Medicaid, which I think in a way, was good. It was good in terms of getting non-disabled people engaged and aware that it's important to everyone.

GREGG: Yeah. I think one of the heartening things has been seeing people realize what value Medicaid adds to our society, that people are able to work and live and raise their families, go to school, give birth to healthy kids because of what Medicaid provides. And I think in that way, Andrew, you're right: It helped Medicaid reclaim its good name. I mean, as you said, no one has been more critical of Medicaid's flaws than the disability community. But we were never advocating doing away with it, but fixing it.

ANDREW: The Republicans, I think, have made a mistake in thinking that complaints about a system mean they have a license to just tear it up, and I just think they're finding out that they kinda don't [chuckles]. Hopefully.

ALICE: Well, right, in the sense that they wanna tear it up and not really even have a plan for something that's similar or comparable or better. I mean, that was a huge, huge, huge red flag, and I think clearly, people saw through that.

GREGG: I think they put their dreams of serving a certain constituency ahead of serving their whole constituency. That's never a good recipe.

ALICE: Well, yeah. I mean, look at Senator McConnell and Kentucky. Kentucky has so many people that need health care.

GREGG: Yes.

ANDREW: Well, that's the hard, hard kernel that we may never fully crack, which is there are people who are fundamentally, they need these things. But for a variety of reasons, they do sort of, on a level, despise them. So, you get lots of people in places like Kentucky who gripe and moan about the fact that their neighbors get Medicaid, and they don't, or this person gets Medicaid and shouldn't. And they complain on that moral plane about freeloaders and all that stuff. And then, the politicians take that and say, "OK. So, clearly my people don't like Medicaid." It's not quite that simple. Even the people that make these sort of really disgusting comparisons and criticisms, that doesn't mean that they don't need it. It doesn't mean that they-- If they could get their heads around it in a different way, they would probably support it.

ALICE: Well, it's also funny that there are those folks all over the country--not just in the middle of the country, not just in the South--but everywhere, they don't realize that the plan that they're on is funded by the ACA.

GREGG: Mmhmm.

ANDREW: Yeah.

ALICE: They may reel against President Obama 'cause let's face it: I think that is a big part of why people were so against it is that this was passed by the first Black president and is something will just never accept that, you know? I think we gotta bring up that sense of hate.

ANDREW: I've heard they're described it where it's like a secret welfare, right? That certain people believe that all the good things that Obama did or that Democrats try to do are for other people not like them, right? And that there are people who take that racism, for instance, of not liking the first Black president, and they take it a step further and say, "Well, all these things are really for his people." Then, you can go into ableism on that and say, "Well, all these disabled people get this, that, and the other thing. I don't get anything." Where in fact, Obamacare took Medicaid and expanded it to people who weren't disabled, who weren't super-duper poor or only moderately poor. So, the thing that they think it should do is exactly what it did, and it just boggles the mind.

GREGG: The interesting thing for me, Alice, you mentioned people all over the country not realizing they're on ACA-funded plans. I think part of what we've seen is people start to realize that they are and that people they know depend on Medicaid across the country. And that's why we've seen so many people come out all over the country. I mean, there were protests in 30 different cities.

ANDREW: That's fantastic.

GREGG: Isn't it?

ANDREW: Yeah.

GREGG: I mean, I'd like to say it was all ADAPT, but there were plenty of people from non-disabled communities that stepped out and got in line and said, "I'm against this too."

[clapping and bouncy jazz]

The Summer of ADAPT

ALICE: Speaking about protests, I do think that one of the most visible and really just captured the moment so well is this whole summer of ADAPT. You are a member of ADAPT, Gregg, and

you were at the Capitol. You were arrested in front of Senator McConnell's office along with, what was it, 40?

GREGG: McConnell's, I believe, was about 45. I could be--

ALICE: Yeah, about 45 other folks. I think that event especially really started the ball, and you all were protesting way before that. Why don't you tell us a little bit about, I guess, your activity with ADAPT this year and just what you thought in terms of what you saw on the ground and just the importance of direct action?

GREGG: I mean, I've been asked a lot why things took off with McConnell's office. And part of it may just be luck. We like to say--I've heard Bruce Darling say--"We count on the ADAPT gods who've gone before to look after us." And that may be part of it because it just so happens that McConnell's office is just down the hall from the press office.

ALICE: Ah!

GREGG: And so, they immediately heard us chanting and came out. So, the cameras were there almost from the second we started. I'm told that the policy's changed, and they're actually kept a bit further away now. But you know, I think that was a big part of why the press coverage was there as opposed to say, earlier in the year when we occupied the Capitol Rotunda. But I also think the press were looking for a way to focus on this bill, and they knew people opposed it but didn't have a face or voices to put to it.

ALICE: Mmhmm.

GREGG: So, to an extent, ADAPT gave them that.

ANDREW: You know, I think one of the subtler ways that it worked well was that I think people pretty quickly saw that it was not your typical part--and I wanna say this carefully, but I'm gonna say kind of like--not your typical part of the "resistance." Which is not to say that the resistance is, or all in a broader sense, is unimportant or silly or anything like that. But it was less easy to blow off the ADAPT people and to say, "Oh, it's them again, those people that always protest stuff." Or, "Those people that are the usual suspects in people's minds of who hate Donald Trump," right?

I remember when it was just starting and me, what not, being there but kind of looking from a distance. It was great when some trolls, in the very beginning, started saying, "Oh! These are..." either that you guys were all paid protesters, or worse, that you were just sort of mindless dupes for the socialists and the other parts of the resistance. Like these sort of nefarious big-wigs obtained you guys to go and do it for them. And it was so completely wrong, and it's more wrong than usual because ADAPT--if you know anything about ADAPT--they don't take anybody's orders. Let's put it that way.

GREGG: [chuckles]

ANDREW: And to call ADAPT, or to refer to these ADAPT protesters, as in any way being just sort of foot soldiers, it's like anybody looking at it for a moment would realize how wrong that way. I think that helped a little bit, because people said, "Yeah, you know, you can't just blow these people off. They're in it for real. This is real for them. This is not an ideological game."

GREGG: The thing about ADAPT, I mean, ADAPT can play nice; ADAPT can play uncooperative. It depends on what we're met with. We had a bunch of Republican Senators who generally wouldn't talk to us, who fled, who sent the police to kick us out. In cases where a Senator was willing to listen, we spoke to Collins, Senator Collins, and she was kind enough to listen to us. And no one occupied any offices of hers, because she just sat and talked to us.

ALICE: Right, and I think this is where in terms of different approaches, right? Like, usually direct actions are kind of like, I don't wanna say the last resort, but kind of the secret weapon. You only use it when you absolutely are forced to use it. And I think this is a different thing that a lot of people who are not activists or not interested in activism, they see it as this-- I've seen people ask, "Why can't you work with people? Why can't you tone down the rhetoric? Why can't you be nicer to really get people to cooperate with you?"

And you know, there are people that really, truly believe that that is the way to make change. I think what a lot of them don't realize is that for marginalized folks, we have been trying hard to work within the system, to be conciliatory, to be open-minded, to extend the hand. And oftentimes, we're shut out. You know, there is a place for anger. There is a place for disobedience.

[bluesy-reggae music]

GREGG: Well, I mean, I think where we've had that opportunity, we've taken it. We worked with Representative Sensenbrenner and Senator Schumer to craft the Disability Integration Act. That was ADAPT. That was not us locking ourselves in their office; it was us talking to them. And so, when those opportunities have been available, we've taken them. But yes, as you said, most of the time, the instinct is disabled people, they've got no money to give to campaigns. They may or may not turn out. We don't know, 'cause we have no data. So, let's just ignore them.

ANDREW: For sure. You know, one thing I wanted to say just in general about disability activism right now that I'm kinda happy about is that I don't know if it's on purpose or just by chance, but I like the fact that the disability activism hasn't really, has been really focused and disciplined on issues and their actual effects rather than sort of going along with the obsession with Trump, if you know what I mean. Like, Trump the man, Trump the weirdo. It's not like we don't have those feelings, perhaps, but they're not really part of that, because it's not all that relevant at the moment.

#CriptheVote

ALICE: Yeah, and also the whole idea, the aspect of the resistance is that, all three of us are on Twitter. We've seen just so many different ableist comments about Trump, and about just the way they're talking about the issues. And that in itself is problematic and just goes to show how far we need to go and the fact that most of what we see in terms of disability activism is just very substantive. It's got the bigger picture versus this cult of personality.

GREGG: And we've gotten to see that close up. I mean, the fact is #CriptheVote could've easily degenerated in die like this politician and that politician, but it never did. I mean, to the community's credit, everyone, almost without exception, kept it on the issues, whether it was during debates or whether it was one of the chats we had on a particular topic. It never devolved into partisan crap, or it was always about how this will affect our community.

ALICE: Yeah, I mean, we've been at this for now--talking July 2017--so it's about, we've been in existence for over a year and a half. Originally, we were gonna wrap it up after election day last November. I'm so glad that we decided that no, this community, there's still a huge need for it,

and it's only gonna continue onward. It's much more than just about voting; it's about political participation. It's about having a voice. And it's also about just having a space for conversations.

For the listeners who don't know #CriptheVote, most of our activities are on Twitter, and we have about once a month, roughly about once a month, a Twitter chat about some sort of disability issue.

So, just what were some of the highlights that you both wanna recall from our last four chats?

ANDREW: I think more than any particular chat, what sticks in my mind is that we're continuing with these topics that some of them aren't really on the front burner otherwise. And especially with the health care thing, I mean, it would be understandable if we all did nothing else but think about health care for the last six months. But at least with our chats, we would take a little time each month to look at a topic that's important but maybe has fallen off the radar. And I think that's really important going forward, because there's all kinds of issues that matter to our community that aren't necessarily burning right at the moment, but they could be at any time.

GREGG: I mean, the one on the media, I think, was kind of amazing for me, just seeing the outpouring we got. People were, there was a lot of frustration that people seemed to finally be able to give voice to.

ALICE: I agree. I feel that way about the death penalty chat, because I mean, similar to TL, who also guest-hosted our chat last year on mass incarceration, I feel like I am still really shocked that the death penalty issues are not a priority in terms of the so-called disability rights community.

ANDREW: And that's an evolving process for a lot of people, is evolving from thinking of disability as a fairly simple and narrow range of issues to being things, being something that relates to a huge tent of issues.

ALICE: And there's so many different issues in terms of race, class, and disability that's really just not-- And I think that's another thing that we could do in terms of kinda point in the direction to these issues that may not seem as our issues, but to say that yes, they are our issues.

Wrap-up

["Dance Off" hip hop song]

ALICE: For more about #CriptheVote, you should check out our blog, CripTheVote.blogspot.com. If you're on Twitter, you can use the hashtag #CriptheVote. And follow Gregg @greggberatan and Andrew @AndrewPulrang. You can reach me on Twitter @DisVisibility. For more about ADAPT, go to ADAPT.org.

This podcast is a production of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability media and culture.

All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast.

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If you enjoyed this episode, I'm gonna ask you to do two things: One, subscribe to the Disability Visibility Podcast on iTunes, and support the work of creating disabled media at our Patreon page at Patreon.com/DVP.

Thanks for listening and see you on the Internets!

♪ Rock it to the blast off

Stop drop dance off ♪